Chapter VIII

Pediatric End-Stage Renal Disease

Key Words:
Pediatric ESRD
ESRD incidence in children
ESRD patient survival in children
Pediatric dialysis
Causes of pediatric ESRD
Renal transplants in children
CAPD in children
Hemodialysis in children
Hospitalization admission rates

Children and adolescents with end-stage renal disease (ESRD) are unique with respect to the different etiologies of renal failure, treatment, mortality, and overall patient and transplant graft survival. (McEnery; Fine, Salusky, et al. 1987; Fine 1987; Ettenger). Factors contributing to the differences in the treatment of pediatric ESRD and adult ESRD include development of cognition, secondary sexual characteristics, and physical growth. For these reasons, the pediatric ESRD population requires special attention, and this chapter will focus on the incidence, prevalence, and modalities of treatment, survival outcomes, and cause specific mortality as related to the national pediatric ESRD population.

The reported upper age cutoff for pediatric patients used among the ESRD registries worldwide ranges between 15 and 19 years. As in earlier USRDS Annual Data Reports (ADR), the 1999 ADR defines pediatric as all patients less than 20 years of age. In many of the analyses in this chapter, pediatric patients are further divided into 5-year age groups: 0-4, 5-9, 10-14, and 15-19 years.

Several definitions of age are used in this chapter: 1) age is defined as age at onset of ESRD for analyses of incidence and dialysis patient survival; 2) age on December 31 is used for analyses of point prevalence; and 3) age at time of transplantation is used for analyses of kidney transplants. In all cases, only patients less than 20 years of age are considered here.

Incidence of Reported Pediatric ESRD

Among both the pediatric and adult ESRD populations, rates of ESRD incidence increase substantially with increasing age. The incidence rate of treated ESRD, adjusted for race and sex, is much higher among adults than among children. During 1997 the adjusted ESRD incidence rate per million United States population (in each age group) was 13 for ages 0-19 years, 109 for ages 20-44 years, 545 for ages 45-64 years, 1,296 for ages 65-74 years, and 1,292 for ages 75 and over (Reference Table A.6). A higher ESRD incidence rate with older ages is also found across the 5-year age groups within the pediatric cohort, when adjusting for differences in sex and race. Table VIII-1 indicates that average incidence rates over the combined years 1995-97 were more than twice as high among children 15-19 years (28 per million) compared to children 10-14 years (14 per million), and more than three times higher than rates for children 0-4 (9 per million) and 5-9 (7 per million) years of age at onset of ESRD. Average annual counts of incident ESRD among children for the years 1995-97 show that 509 out of the 1,073 children newly beginning treatment for ESRD (47 percent) were between the ages of 15 and 19 (Table VIII-1). Adolescent children have uniformly represented the largest incident group in

Pediatric ESRD Incidence and Prevalence Counts and Rates, 1995-97

Age at Incidence	Incidence		Point Prevalence*	
	Average Counts Per Year	Unadjusted Annual Rate**	Average Counts Per Year	Unadjusted Annual Rate**
0-4	171	9	381	22
5-9	137	7	750	40
10-14	257	14	1,386	76
15-19	509	28	2,616	143
All Pediatric (0-19)	1,073	15	5,133	70
Adults (20-44)	12,050	123	72,802	732

**Alive on December 31 of 1995-97. **Per million population (in each group), adjusted for sex and race. Patients in Puerto Rico and U.S. Territories and cases where race is "other" or "unknown" are excluded. Counts are averaged over a three year period.*
Source: Reference Tables A.3, A.4, B.5, and B.6

Table VIII-1 ***USRDS 1999***

the pediatric ESRD population from the 1995 to 1997 cohorts.

The average counts per year of incident pediatric ESRD patients have had small incremental increases from 1989-91 cohort to the 1995-97 cohort (Figure VIII-1). Correspondingly, there is an increase in annual incidence rates for the total pediatric incident group from 12 in the 1988-91 cohort to 15 in the 1995-97 cohort (Table VIII-1). The small increases seen in the previous two years were considered to be due to the inclusion of non-Medicare patients in the 1994-95 incident patient counts reported by the Health Care Financing Administration (HCFA). However, there have been consistent, albeit, small increases each year in the total average counts. This increase is not consistent in all pediatric age groups. The youngest age group 0-4 and the oldest age group 15-19 have the greatest increases in counts per year. This may indicate an increase in diagnosis and treatment for the very young patients with ESRD.

Within the pediatric ESRD population, there are large variations in the incidence rates of ESRD by race, as well as by age. The pediatric treated ESRD overall incidence rates per million United States population per year for the 1995-97 period were 12 for Whites, 27 for Blacks, 15 for Asians/Pacific Islanders, and 17 for Native Americans (Reference Table A.31). The higher overall incidence of ESRD for Black children was primarily the result of an almost three-fold excess of ESRD among Blacks compared to Whites, in the 15-19-year-old age group (60 per million versus 20 per million). Treated ESRD incidence rates in Whites and Blacks differed less in the younger age groups (Figure VIII-2). The incidence rates for Native Americans and Asians show a similar pattern compared to Whites, with a rate of 31 per million and 32 per million respectively between the ages of 15-19. The overall Native American incidence rate of 17 per million population per year for the 1995-97 cohort is lower than the previous reported incidence rate of 21 per million population per year for the 1994-96 cohort (USRDS 1998).

Figure VIII-3 illustrates the incidence of treated ESRD by sex, according to 5-year age groups. Treated incidence rates of ESRD were greater for boys than girls overall. This reflects the higher incidence of congenital disorders including obstructive uropathy, renal dysplasia, and Prune Belly syndrome that occur more commonly in boys, and are the cause of approximately 17 percent of the total incident cases in the pediatric ESRD population.

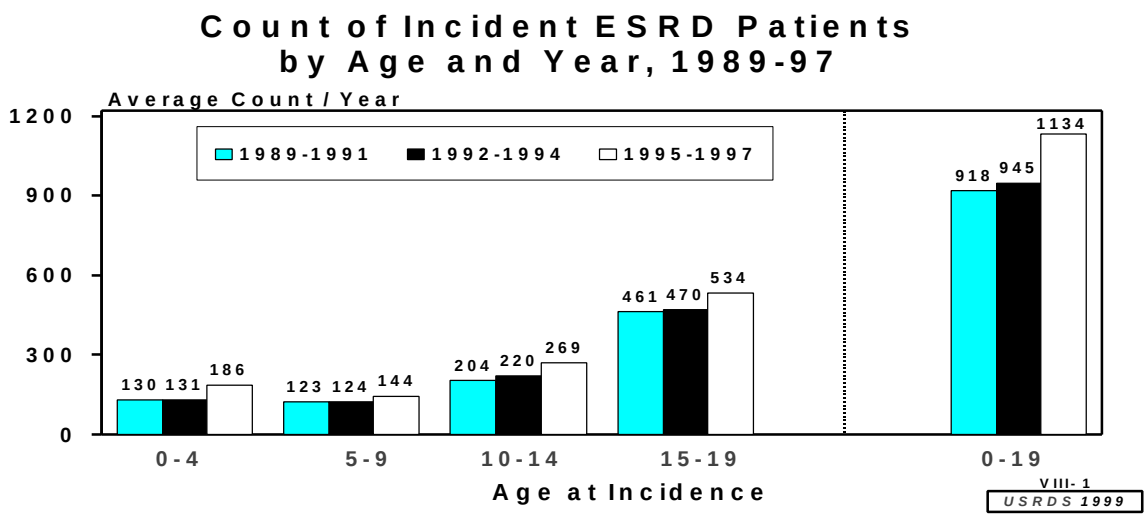

Figure VIII-1

Average Count per year (1989-91, 1992-94, and 1995-97) of incident ESRD patients by age group. Source: Reference Table A.1.

Causes of Pediatric ESRD

The incidence of reported ESRD therapy by detailed primary disease group for pediatric patients is shown in Tables VIII-2 and VIII-3. Counts and percentages for Asian/Pacific Islander and Native American patients are not presented due to small cell sizes, which makes detecting true patterns more difficult. Estimates shown in Tables VIII-2 and VIII-3 have not been adjusted for differences in age, race, sex, and modality of care across disease groups. Table VIII-2 represents the descriptive statistics for the incident pediatric cohort from 1993-97 by cause of ESRD, median age, sex, race, 1-year transplant and

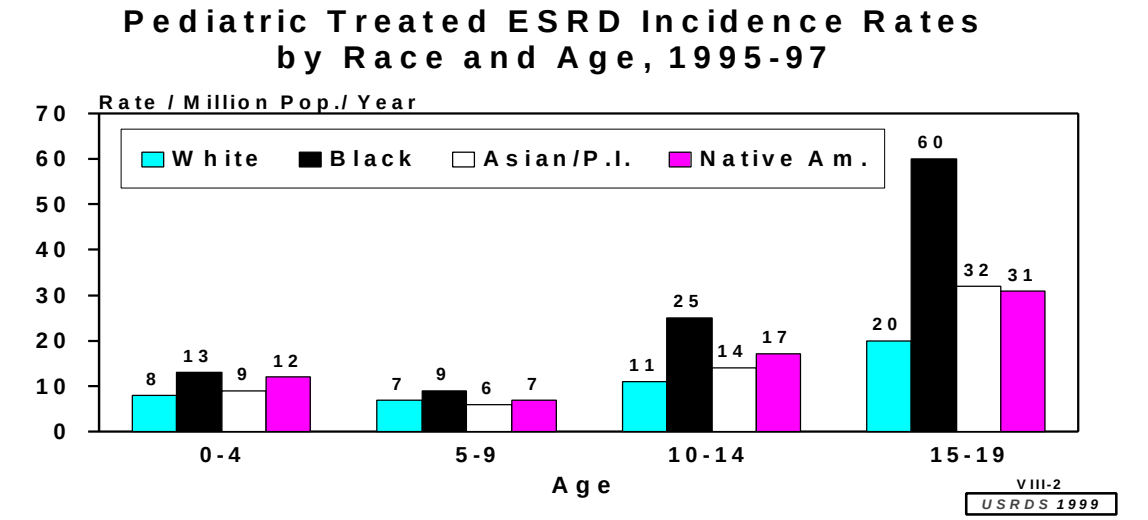

Figure VIII-2

Reported average pediatric ESRD incidence rates per million population per year by age group and race, 1995-97. Incidence rates for children (ages 0-19 years) are adjusted for sex. Patients in Puerto Rico and U.S. Territories, and cases where race is "other" or "unknown" are excluded. Source: Reference Tables A.8 and A.31.

death status. During the four years, there were 5,431 incident cases of ESRD in children. Fifty seven percent were boys and 62 percent were White. Within the first year of therapy, 44 percent were transplanted. This has gone up significantly from 37 percent in last year's 1992-96 cohort (USRDS 1998). As the cohort years overlap for 2 years, it indicates a significant increase in transplantation in 1997.

This represents a much higher overall transplant rate than in the adult population. Interstitial nephritis and cystic/hereditary/congenital disorders have greater than 50 percent of the patients transplanted during the first year.

The etiology of pediatric ESRD is substantially different from causes of ESRD in adults. The largest single disease group causing ESRD in children is primary glomerulonephritis (GN) (approximately 30 percent of all reported causes), followed by cystic/hereditary/congenital diseases (26 percent). The next most common causes for pediatric ESRD are interstitial nephritis (9 percent) and collagen vascular disorders (secondary GN; 9 percent). Some other disease categories of interest include hypertension, diabetes, polycystic kidney disease and AIDS nephropathy (Table VIII-3). Hypertension only represented 4.5 percent of all pediatric causes of ESRD as compared to approximately 19 percent in adults aged 20-64 and 31 percent in ages over 65 (Reference Tables A.18 and A.20). Diabetes is an extremely rare cause of ESRD in the pediatric population, and accounts for less than 2.0 percent of primary causes of ESRD. Approximately half of the diabetic ESRD patients have type 2 diabetes or unspecified type with a median age of 3 (Reference Table A.21). This represents some misclassification of diabetes as the primary cause of ESRD in the pediatric population as opposed to an associated co-morbidity. The distribution of polycystic kidney disease also reveals a larger proportion is autosomal dominant (adult) and not autosomal recessive (infantile) disease. Previous USRDS ADRs from 1994 to 1997 reported low incident counts (less than 10) of autosomal recessive kidney disease in the pediatric age groups. The increase in the counts of autosomal recessive disease may not represent a true change in incidence rate but it may reflect a change in the reporting of this disease group. AIDS nephropathy now accounts for 0.4 percent of the total incident pediatric ESRD population. It is suspected that there is under-reporting in this disease category. Of the total 5,431 incident pediatric patients, only 8 percent had missing data on the cause of ESRD.

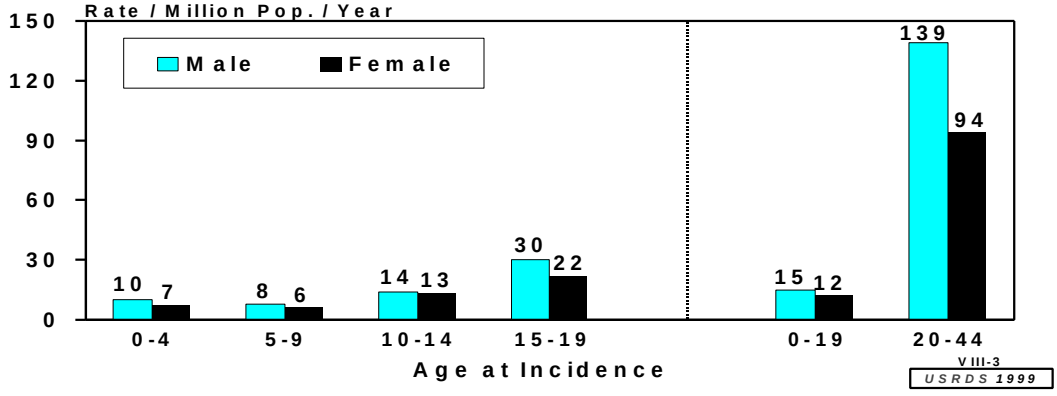

Figure VIII-3

Reported average pediatric ESRD incidence rates per million population per year by sex and age group, 1995-97. Includes all children (ages 0-19 years). Rates are adjusted for race. Patients in Puerto Rico and U.S. Territories, and cases where race is "other" or "unknown" are excluded. Source Reference Tables A.8 and A.31.

Incidence of Treated ESRD (%) in Pediatric Patients (Age<20), Median Age, Sex, Race, and One-Year Transplant and Death Status by Detailed Primary Disease, 1993-97: *Row Percent*[1]

Primary Disease Groups[2]	Total # Patients	Median Age	% Males	% White	% Black	During 1st Year[3] % Tx'ed	During 1st Year[3] % Died
All Pediatric ESRD (reference)	**5,431**	**14**	**57.1**	**62.4**	**27.1**	**44.4**	**3.2**
Diabetes[4]	**89**	**16**	**42.7**	**50.6**	**39.3**	**12.4**	**2.2**
Glomerulonephritis (GN)	**1,620**	**16**	**55.2**	**56.8**	**32.5**	**38.0**	**1.5**
- Focal glomerulosclerosis, focal GN	555	15	60.5	46.3	45.2	37.8	1.8
- Membranous nephropathy	29	16	44.8	44.8	51.7	24.1	3.4
- Membranoproliferative GN	138	16	46.4	68.8	22.5	42.8	0.0
- IgA nephropathy, Berger's disease	86	17	68.6	72.1	*	44.2	0.0
- Rapidly progressive GN	113	14	40.7	64.6	17.7	38.9	0.9
- Goodpastures Syndrome	37	16	48.6	89.2	*	16.2	2.7
- Unspecified GN	562	16	54.8	57.1	30.2	37.5	1.6
- Other proliferative GN	81	16	54.3	64.2	25.9	44.4	1.2
Secondary GN/Vasculitis	**485**	**15**	**35.9**	**61.4**	**26.0**	**21.4**	**6.2**
- Lupus erythematosus	252	17	23.4	44.4	39.3	9.1	7.5
- Wegener's granulomatosis	40	16	47.5	82.5	*	30.0	2.5
- Henoch-Schönlein syndrome	45	14	51.1	88.9	*	48.9	2.2
- Hemolytic uremic syndrome	106	8	55.7	82.1	12.3	34.0	6.6
Interstitial Nephritis/Pyelonephritis	**494**	**14**	**61.3**	**76.5**	**17.4**	**50.0**	**2.6**
- Chronic pyelonephritis, reflux neph.	147	14	44.2	80.3	13.6	47.6	2.0
- Nephropathy caused by other agents	48	15	68.8	79.2	*	52.1	2.1
- Nephrolithiasis, Obstruction, Gout	176	12	74.4	76.1	20.5	49.4	2.8
- Chronic interstitial nephritis	106	15	62.3	74.5	16.0	58.5	3.8
Hypertensive/large vessel disease	**262**	**17**	**57.3**	**37.0**	**54.2**	**26.0**	**4.6**
- Hypertension, (no primary renal dis.)	244	18	58.6	34.4	57.0	25.0	4.5
- Renal artery stenosis or occlusion	18	10	38.9	72.2	*	38.9	5.6
Cystic/Hereditary/Congenital Diseases	**1,410**	**10**	**67.5**	**72.1**	**18.6**	**53.7**	**3.6**
- Polycystic kidneys, adult (dominant)	110	10	47.3	70.9	18.2	48.2	2.7
- Polycystic, infantile (recessive)	52	4	42.3	78.8	*	28.8	11.5
- Medullary cystic, nephronophthisis	60	13	51.7	80.0	*	58.3	1.7
- Alport's, other hereditary/familial disease	148	16	87.2	70.3	21.6	52.7	0.7
- Cystinosis	38	12	60.5	89.5	*	68.4	0.0
- Primary oxalosis	19	3	47.4	84.2	*	52.6	0.0
- Congenital nephrotic syndrome	64	2	43.8	65.6	*	40.6	7.8
- Congenital obstructive uropathy	362	11	81.2	71.8	19.1	62.7	3.3
- Renal hypoplasia, dysplasia	481	8	61.3	70.5	19.8	52.4	4.4
- Prune belly syndrome	61	7	96.7	75.4	19.7	49.2	3.3
- Other Cystic/Hereditary/Congenital Dis.	15	18	66.7	60.0	*	33.3	0.0
Neoplasms/Tumors	**38**	**7**	**47.4**	**65.8**	*****	**23.7**	**21.1**
- Renal or urological neoplasms	37	6	48.6	64.9	*	24.3	21.6
Miscellaneous Conditions	**204**	**12**	**54.4**	**57.4**	**33.8**	**33.3**	**8.3**
- Sickle cell disease/anemia or trait	17	19	58.8	*	94.1	5.9	0.0
- AIDS nephropathy[5]	23	16	65.2	13.0	82.6	0.0	30.4
- Tubular necrosis (no recovery)	55	7	52.7	72.7	18.2	27.3	7.3
Etiology Uncertain	**387**	**15**	**50.4**	**60.5**	**27.1**	**42.4**	**1.3**
Missing	**442**	**13**	**59.5**	**58.1**	**25.3**	**82.8**	**2.5**

Patients in Puerto Rico and U.S. Territories are included. Bolded rows represent disease category headings. [1]Percentages are expressed relative to the number of patients in each disease group (row percent). Percentages for Asian and Native American patients are not shown because of small cell sizes. [2]Primary diseases with < 20 cases total are not listed separately from the corresponding disease group unless otherwise noted. [3]"1st Year" = 1st year of ESRD therapy; "Tx'ed" = transplanted. [4] Some patients may have been misclassified. [5]Underreporting suspected. *Less than 10 patients per cell. Source: Reference Table A.21.

Table VIII-2 ***USRDS 1999***

Incidence of Treated ESRD in Pediatric Patients (Age<20) by Detailed Primary Disease and Race, 1993-97: *Column Percent*[1]

Primary Disease Groups[2]	Total Patients (5 years)	% of Total	# White	# Black	Percent White	Percent Black
All Pediatric ESRD (reference)	**5,431**	**100.0**	**3,388**	**1,472**	**100.0**	**100.0**
Diabetes[3]	**89**	**1.6**	**45**	**35**	**1.4**	**2.6**
Glomerulonephritis (GN)	**1,620**	**29.8**	**920**	**526**	**29.4**	**38.7**
- Focal glomerulosclerosis, focal GN	555	10.2	257	251	8.2	18.5
- Membranous nephropathy	29	0.5	13	15	0.4	1.1
- Membranoproliferative GN	138	2.5	95	31	3.0	2.3
- IgA nephropathy, Berger's disease	86	1.6	62	10	2.0	0.7
- Rapidly progressive GN	113	2.1	73	20	2.3	1.5
- Goodpastures Syndrome	37	0.7	33	*	1.1	*
- Unspecified GN	562	10.3	321	170	10.3	12.5
- Other proliferative GN	81	1.5	52	21	1.7	1.5
Secondary GN/Vasculitis	**485**	**8.9**	**298**	**126**	**9.5**	**9.3**
- Lupus erythematosus	252	4.6	112	99	3.6	7.3
- Wegener's granulomatosis	40	0.7	33	*	1.1	*
- Henoch-Schönlein syndrome	45	0.8	40	*	1.3	*
- Hemolytic uremic syndrome	106	2.0	87	13	2.8	1.0
Interstitial Nephritis/Pyelonephritis	**494**	**9.1**	**378**	**86**	**12.1**	**6.3**
- Chronic pyelonephritis, reflux neph.	147	2.7	118	20	3.8	1.5
- Nephropathy caused by other agents	48	0.9	38	*	1.2	*
- Nephrolithiasis, Obstruction, Gout	176	3.2	134	36	4.3	2.6
- Chronic interstitial nephritis	106	2.0	79	17	2.5	1.3
Hypertensive/large vessel disease	**262**	**4.8**	**97**	**142**	**3.1**	**10.4**
- Hypertension, (no primary renal dis.)	244	4.5	84	139	2.7	10.2
- Renal artery stenosis or occlusion	18	0.3	13	*	0.4	*
Cystic/Hereditary/Congenital Diseases	**1,410**	**26.0**	**1017**	**262**	**32.5**	**19.3**
- Polycystic kidneys, adult (dominant)	110	2.0	78	20	2.5	1.5
- Polycystic, infantile (recessive)	52	1.0	41	*	1.3	*
- Medullary cystic, nephronophthisis	60	1.1	48	*	1.5	*
- Alport's, other hereditary/familial disease	148	2.7	104	32	3.3	2.4
- Cystinosis	38	0.7	34	*	1.1	*
- Primary oxalosis	19	0.4	16	*	0.5	*
- Congenital nephrotic syndrome	64	1.2	42	*	1.3	*
- Congenital obstructive uropathy	362	6.7	260	69	8.3	5.1
- Renal hypoplasia, dysplasia	481	8.9	339	95	10.8	7.0
- Prune belly syndrome	61	1.1	46	12	1.5	0.9
- Other Cystic/Hereditary/Congenital Dis.	15	0.6	25	*	0.8	*
Neoplasms/Tumors	**38**	**0.7**	**25**	*****	**0.8**	*****
- Renal or urological neoplasms	37	**0.7**	24	*****	0.8	*****
Miscellaneous Conditions	**204**	**3.8**	**117**	**69**	**3.7**	**5.1**
- Sickle cell disease/anemia or trait	17	0.3	*	16	*	1.2
- AIDS nephropathy[4]	23	0.5	*	19	*	1.4
- Tubular necrosis (no recovery)	55	1.1	40	10	1.3	0.7
Etiology Uncertain	**387**	**7.1**	**234**	**105**	**7.5**	**7.7**
Missing	**442**	**8.1**	**257**	**112**	******	******

Patients in Puerto Rico and U.S. Territories are included. Bolded rows represent disease category headings. [1]Percentages are expressed relative to the number of patients in race, i.e., totals (bolded) add to 100% for the percent of total column. Counts and percentages for Asian and Native American patients are not shown because of small cell sizes. [2]Primary diseases with < 20 cases total are not listed separately from the corresponding disease group unless otherwise noted. [3]Some patients may have been misclassified. [4]Underreporting suspected. *Less than 10 patients per cell. **Percent distribution excludes missing. Source: Reference Table A.22.

Table VIII-3

USRDS 1999

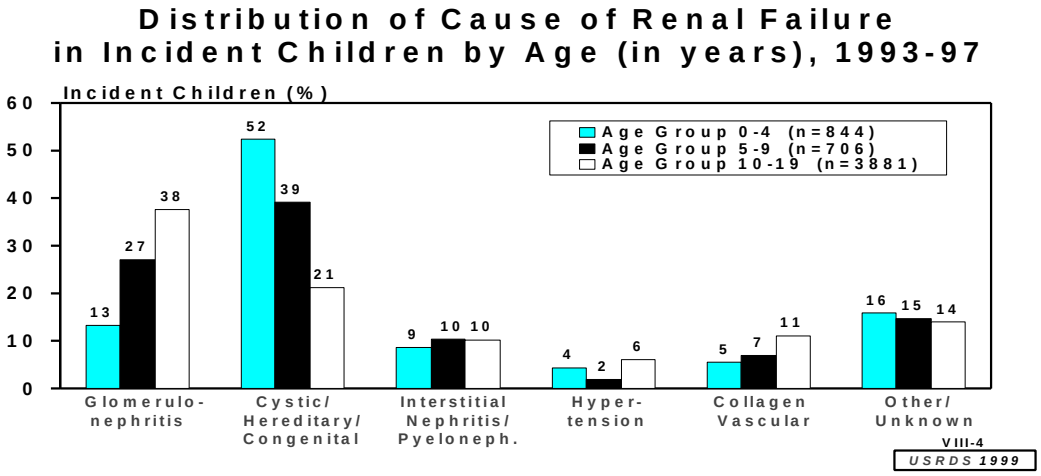

Figure VIII-4

Incident pediatric cases by disease group, by age group (0-4, 5-9, and 10-19), as a percent of total pediatric ESRD cases within each age group. Numbers on top of bars represent the percent within each age group over a 5-year time period, 1993-1997. Patients in Puerto Rico and U.S. Territories are included. Source: Special Analysis.

The distribution of causes of ESRD by age group for pediatric incident patients during 1993-97 is shown in Figure VIII-4. Among patients 0-4 years old, cystic/hereditary/congenital diseases were the primary cause of ESRD. Among the older patients (5-9 years of age at onset of ESRD), both cystic/hereditary/congenital diseases and glomerulonephritis (GN) were prominent. In contrast, the oldest age group (10-19) had a significantly higher incidence of glomerulonephritis compared to the youngest age groups. Interstitial nephritis and pyelonephritis incidence rates did not vary by age group.

Figure VIII-5 provides the distribution of causes of ESRD within each race group for pediatric incident

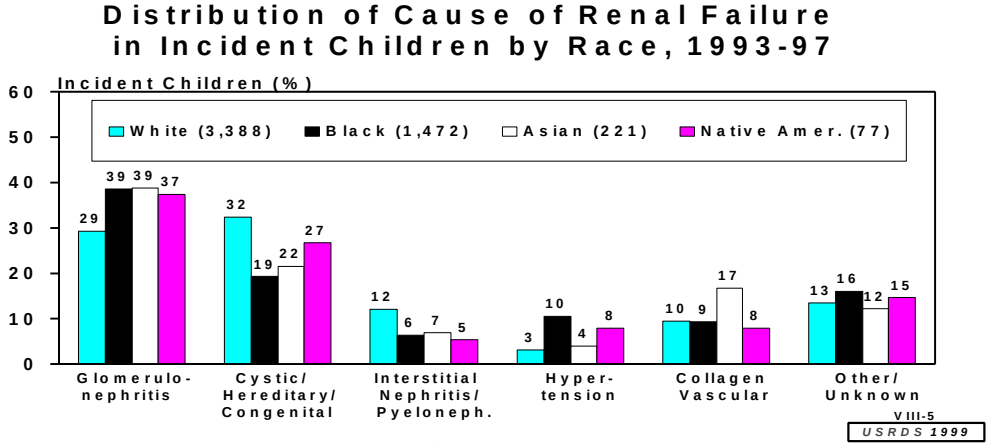

Figure VIII-5

Incident pediatric cases by disease group, and by race, as a percent of total pediatric ESRD for that race. Percentages within each panel add to 100. Total excludes missing disease. Average percent over a 5-year period, 1993-97. Patients in Puerto Rico and U.S. Territories are included. Source: Reference Tables A.21 and A.22.

patients during 1993-97. Primary GN was the primary cause of ESRD in 39 percent of Blacks, 39 percent of Asians, 37 percent of Native Americans, and 29 percent of Whites. Hypertension was the primary cause of ESRD in only 10 and 8 percent of Blacks and Native Americans respectively, and was a rare cause among Whites and Asians.

Among White children, the etiology of ESRD was similar in the primary GN group (29 percent), and the Cystic/hereditary/congenital diseases group (32 percent). In the Asian/Pacific Islander children, primary and secondary glomerulonephritis (collagen vascular disease) accounted for 56 percent of the causes for ESRD. A similar pattern was also seen in the Black children with 48 percent of ESRD caused by primary and secondary glomerulonephritis.

By disease category, focal segmental glomerulosclerosis (FSGS) comprised the biggest specified diagnosis (26 percent) in the primary and secondary glomerulonephritis categories. In FSGS, 60 percent were boys, 46 percent were White, 45 percent were Black, and less than 2.0 percent were transplanted in the first year. In Lupus ESRD patients, females constituted 77 percent of the group, 45 percent were White and 9.1 percent were transplanted in the first year. In hemolytic uremic syndrome, 82 percent were White and the median age was relatively young at 8 years (Table VIII-2).

Cystic/hereditary/congenital diseases account for 26 percent of the causes of ESRD; the median age is 10, 68 percent are male and 72 percent are White. Children with cystic/hereditary/congenital diseases had a 10 percent increase in the number of transplants performed during the first year of ESRD therapy compared to the 1992-96 cohort (USRDS 1998).

Interstitial nephritis was the third most common cause of pediatric ESRD and comprised 9 percent of the total incident cases from 1993-1997. Of this group, 61 percent were male, 77 percent were White and 50 percent were transplanted in the first year.

Blacks accounted for an average of 27 percent of the total incident pediatric ESRD population between 1993-97 and were particularly over-represented among children whose primary cause of ESRD was hypertension (54 percent). Whites represented 62 percent of the total incident cohort 1993-97. Among the primary disease group, interstitial nephritis, almost 77 percent were White. In the cystic/hereditary/congenital diseases, 72 percent were White and in the secondary GN/vasculitis group, 61 percent were White.

A higher proportion of children with ESRD were male (57 percent), particularly among patients with ESRD due to cystic/hereditary/congenital diseases (68 percent) and interstitial nephritis (61 percent).

Treatment Modality at 2 Years Following ESRD Onset, by Age, 1992-94 Incident Cohort

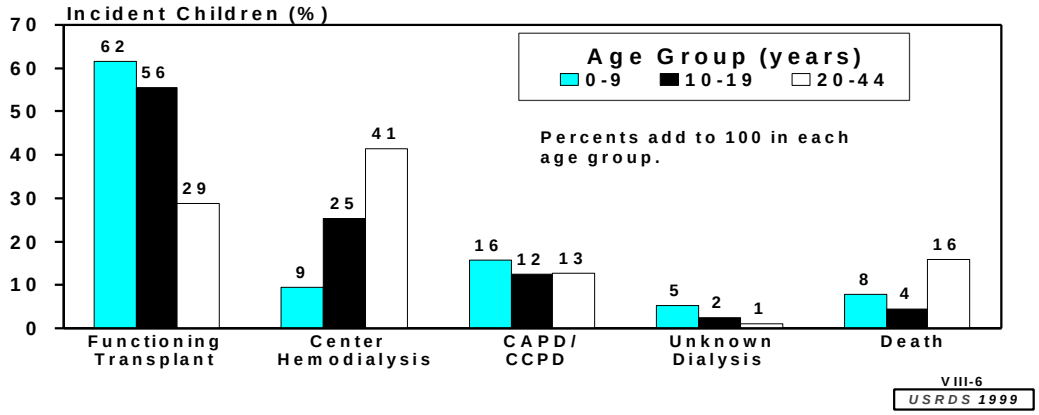

Figure VIII-6

Renal replacement therapy at two years (+91 days) post onset of ESRD, by age at onset, 1992-94 cohort of treated incident pediatric patients. Percentages within each age group add to 100. Patients in Puerto Rico and U.S. Territories are included. Source: Reference Tables C.9 and C.10.

The fraction of pediatric ESRD patients who died within 1-year following onset of ESRD was highest among those with neoplasms, miscellaneous conditions, secondary GN/ vasculitis (especially lupus and hemolytic uremic syndrome), and hypertension. However, in the category of cystic/hereditary/congenital diseases, there were two groups with markedly elevated deaths in the first year of ESRD therapy: autosomal recessive polycystic disease, and congenital nephrotic syndrome. Mortality was lowest among pediatric patients with ESRD due to primary GN.

Prevalence of Reported Pediatric ESRD

Point prevalence counts and age specific prevalence of treated ESRD per million population in the United States are shown in Table VIII-1. The aggregated pediatric numbers (ages 0-19) are compared with data for the 20-44 year age group. As children grow older, they will be counted as prevalent in successively older age groups. For example, a child incident (i.e., new to ESRD) at age 4 in 1987 would be counted as prevalent in the 10-14-year age group (age 12), if still alive in 1995. Point prevalence per million population reveal an approximate doubling of prevalence for successively older 5-year age groups (Table VIII-1).

Average point prevalence counts for pediatric patients (adjusted for age, race, and sex) are increased for the time period 1995-97 (66 per million population) compared to 1994-96 (64 per million population; Reference Table B.8). As stated earlier, this increase in point prevalence is attributable to the higher incident counts. The increasing number of pediatric ESRD patients will have an effect on the required number of health care personnel.

ESRD Treatment Modalities for Pediatric Patients

Children with ESRD have special needs and requirements that strongly influence preferences for treatment and patterns of treatment utilization (Held; USRDS 1991). There are substantial differences in treatment modality utilization between adult and pediatric patients (Alexander; Held). Children are more likely to have peritoneal dialysis than are adults, and younger children are much more likely to receive a renal transplant than are older children and adult patients (Alexander; Held; Mehls; Kohaut). Evidence of reduced growth rates for children receiving dialysis compared to those receiving a transplant (Turenne; Tejani) also contributes to a strong preference for kidney transplantation for children (Alexander; Webb). There has been an improvement in survival of infants receiving transplants, so that age is no longer a factor in determining eligibility for transplantation (Kohaut).

Several other factors have contributed to differences between the adult and pediatric ESRD treatment modality use. These include the relatively greater availability of living kidney donors (particularly parental) for pediatric transplantation (Bloembergen), limitations on educational, social and emotional support for patients treated with center hemodialysis, problems associated with obtaining vascular access for dialysis in small children, and the need for less constraints on dietary and fluid intake with peritoneal dialysis compared to hemodialysis.

The largest difference in methods of treatment for the pediatric versus the adult ESRD population is seen in transplantation. Forty-four percent of children starting ESRD therapy during the 1993-97 time period had received a transplant during the first year (Table VIII-2), compared to only 10 percent of patients 20-64 years of age at ESRD incidence (Reference Table A.19).

The treatment modality at 2 years following onset of ESRD is shown in Figure VIII-6. Sixty-two percent of children between the ages of 0-9 years and 56 percent of children 10-19 years of age had a functioning graft after 2 years of ESRD therapy. Thirty percent of children age 0-9 were on dialysis at 2 years, with predominantly 16 percent on peritoneal dialysis. The oldest age group (10-19) had a higher proportion on hemodialysis (25 percent) than on peritoneal dialysis (12 percent). In contrast, only 29 percent of adults in the 20-44 age group had a functioning graft after 2 years of ESRD therapy and approximately 55 percent were receiving some form of dialysis.

Eight percent of children 0-9 years of age and 4 percent of children 10-19 years of age died within 2 years of onset of ESRD. By comparison, almost 16 percent of incident ESRD patients between 20-44 years had died within 2 years of onset of ESRD.

The differences in patterns of treatment between younger and older children are not as striking as reported for earlier years. Overall, the most favored renal replacement modality is transplantation, in all pediatric age groups. Peritoneal dialysis is still the favored mode of dialysis in young children ages 0-9.

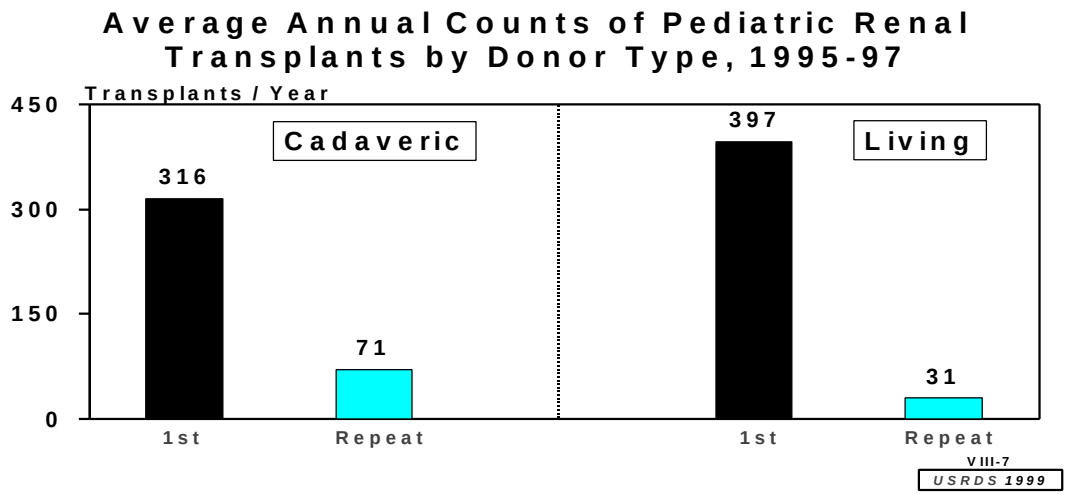

Figure VIII-7

Average annual counts of pediatric renal transplants by donor type (cadaveric or living) and transplant number (first or repeat) performed during 1995-97. Patients in Puerto Rico and U.S. Territories are included. Source: Table F.11 and Special Analysis.

However, there has been an increase in hemodialysis utilization in this youngest age group compared to the 1991-93 cohort (USRDS 1998).

Number of Pediatric Renal Transplants

The number of pediatric renal transplants performed in 1995-97 is shown in Figure VIII-7, according to the transplant number (first or repeat) and type of donor (cadaveric or living). Living donor transplants constitute both living related and unrelated. In the pediatric population, the number of first living donor transplants (397) outnumbered cadaveric donor transplants (316). This is in marked contrast to the adult population (ages 20-64), for whom first cadaveric transplants are 2 to 3 times more common than first living donor transplants (Reference Table F.2). The average annual count of living transplants for 1995-97 (397) has increased compared to 1995-96 (374) indicating a significant increase of first living donor transplants in 1997 (USRDS 1998). Overall, the increase in living donor transplants may reflect the clinical practice of early preemptive transplantation.

Access to Kidney Transplantation: Transplantation Rates

This section further characterizes the patients who received kidney transplants, according to the type of donor (cadaveric or living) as well as the age, sex, and race of the transplant recipient. Shown in Figure VIII-8 are pediatric transplantation rates by donor type and recipient age at time of transplantation, for transplants occurring in 1995-97. The transplant rate is calculated as the number of total transplants (first and repeat) performed for a given cohort of patients per 100 dialysis patient years. Data came from the same cohort of patients for the dialysis years (used in the denominator) and the number of transplants (used in the numerator). The number of patients who were transplanted without receiving prior dialysis contributes only to the numerator. Dialysis patient years at risk represents the duration (measured in days and converted to years) that children in the same age, sex, and race group received dialysis therapy during calendar year 1997.

Figure VIII-8 indicates that for children ages 0-19 years, there were 29 living related donor transplants per 100 dialysis patient years, and 27 cadaveric transplants per 100 dialysis patient years during 1995-97. Rates of transplantation were considerably lower in the young adult patients, 20-24 years of age, at 11 and 13 per 100 dialysis patient years for living and cadaveric transplants, respectively. Among patients 5-9 years of age, transplantation rates of living donor (46 per 100 dialysis patient years) and cadaveric (40 per 100 dialysis patient years) transplants were the highest in the pediatric cohort. These rates have increased compared to last year's (1994-96) rates of 39 and 34 per 100 dialysis patient

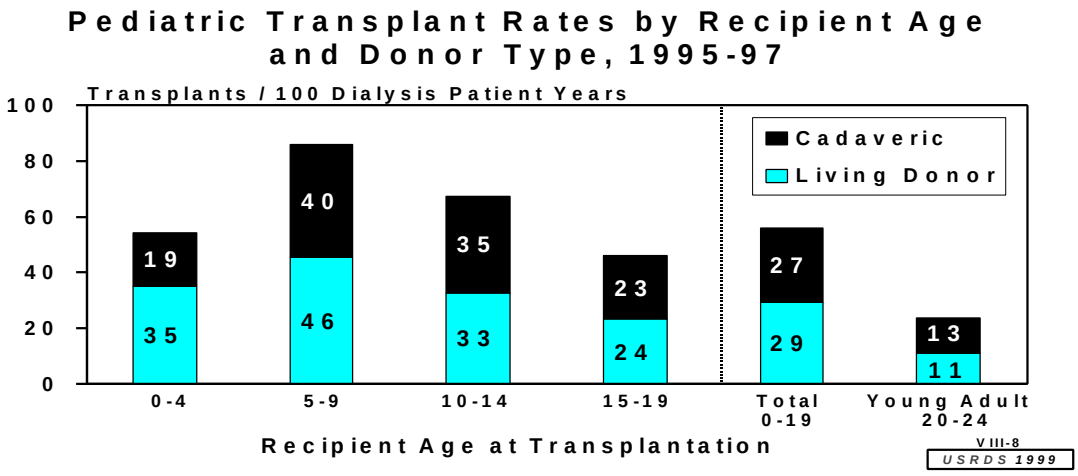

Figure VIII-8

Pediatric renal transplantation rates (per 100 dialysis patient years) for all transplants, by recipient age (on December 31 of transplant year) and donor type, 1995-97. Patients in Puerto Rico and U.S. Territories are included. Source: Special Analysis.

years, living and cadaveric, respectively (USRDS 1998).

Living related transplants were more common than cadaveric transplants in children 0-4 years old. Transplantation rates for cadaveric versus living transplant were similar in the 5-9, 10-14, and 15-19 age groups. The teenagers ages 15-19 had the lowest transplant rate of all pediatric age groups. Overall, the pediatric transplant rates in 1995-97 for both

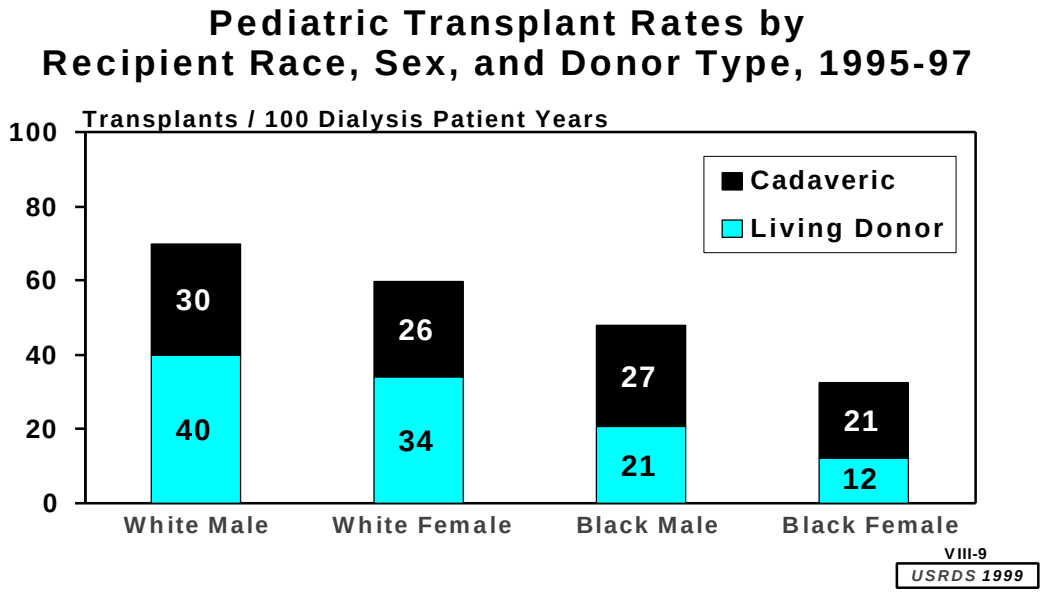

Figure VIII-9

Average pediatric renal transplantation rates (per 100 dialysis years) for all transplants, by donor type, recipient race and sex, 1995-97. Patients in Puerto Rico and U.S. Territories are included. Source: Special Analysis.

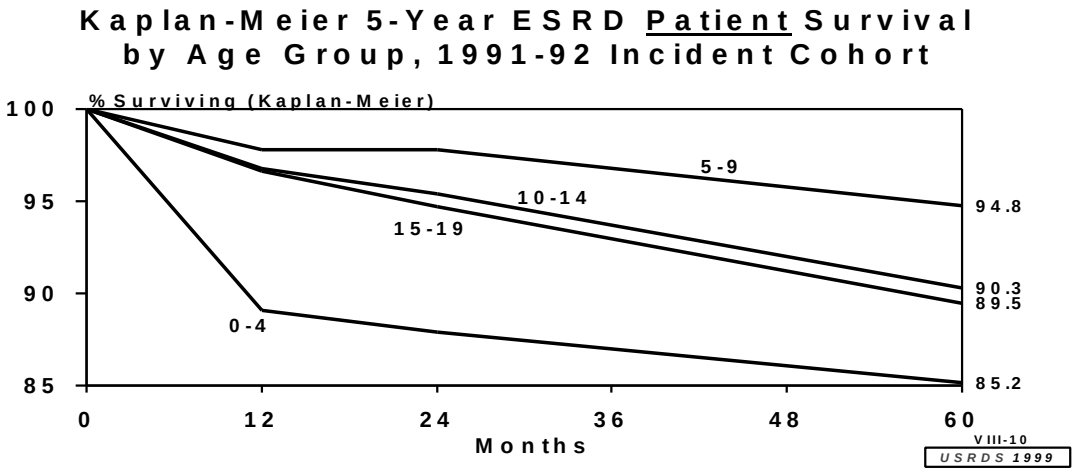

Figure VIII-10

Pediatric Kaplan-Meier 5-year patient survival estimates (percent) by age groups 1991-92 incident cohort. Includes dialysis and transplant patients. Estimates are unadjusted. Survival starting at day 91 following onset of ESRD. Patients in Puerto Rico and U.S. Territories are included in estimates. Source: Reference Tables E.2, E.14, E.16, and E.18.

living and cadaveric donor are significantly increased compared to the 1994-96 cohort especially in young children age 0-9 years.

Transplantation rates by recipient's race and sex are shown for both cadaveric and living related donors in 1995-97 (Figure VIII-9). For girls, the rate of pediatric transplants was lower in Black girls than in White girls for both cadaveric and living transplants. The rate of pediatric living donor transplantation was lower in Black patients of both sexes than for White patients, and the rate for Black females was lowest of the four groups. Females of both races received fewer cadaveric and living donor transplants than males.

Patient Survival for All Renal Replacement Therapies

Figure VIII-10 depicts the unadjusted Kaplan-Meier 5-year patient survival estimates, by 5-year age groups, for all pediatric ESRD patients (includes dialysis and transplantation) in the 1991-92 cohort.

Five-year unadjusted survival estimates for treated pediatric ESRD patients have been relatively constant. The youngest age group (0-4 years) experienced the lowest 5-year survival of 85.2 percent. The greatest decrease in survival occurs at 12 months of therapy and then levels off over 5 years. For the remaining pediatric age groups 5-9, 10-14, and 15-19 years, 5-year survival estimates were 94.8, 90.3 and 89.5 percent, respectively.

Patient Survival by Type of Transplant

Unadjusted Kaplan-Meier 5-year survival estimates for the pediatric patients (1991-92 transplant cohort) receiving cadaveric and living transplants are shown in Figure VIII-11 and Figure VIII-12.

Among cadaveric transplant recipients, the youngest age group (0-4) had the lowest 5-year survival of 90.2 percent; this was improved compared to the five-year survival of 86.7 in the 1990-91 cohort (USRDS 1998). The youngest age group (age 0-4) had a large initial drop in survival over the first year. The decrease in survival over the first year for ages 0-4 was similar to all ESRD (including dialysis and transplantation) 5-year survival. The other three age groups had similar 5-year survival estimates, which ranged from 92-96 percent. In the ages 10-14, 108 patients were followed and in the first 2 years, the patients had 100 percent survival.

Living donor transplant recipients ages 0-4, 5-9, 10-14 and 15-19 in the cohort 1991-92 had a 94.3, 98.5, 93.9 and 94.0 percent 5-year survival, respectively. Overall, living donor recipients had a

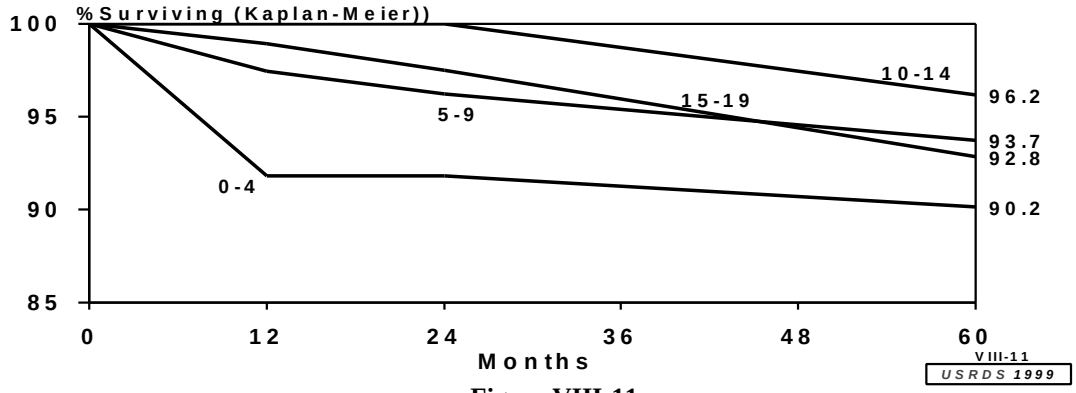

Figure VIII-11

Pediatric Kaplan-Meier 5-year patient survival estimates (percent) by age groups for all cadaveric transplant patients, 1991-92 transplant cohort. Estimates are unadjusted. Survival followup starting from date of transplant. Patients in Puerto Rico and U.S. Territories are included in estimates. Source: Reference Tables E.7, E.62, E.64, and E.66.

higher unadjusted 5-year survival estimate in the 1991-92 cohort compared to the cadaveric transplant patients. In the years 1991 and 1992, 114 patients age 5-9 were followed and had 100 percent survival.

Since there was no adjustment for race, sex, primary diagnosis, or case severity in these survival estimates, it would be inappropriate to infer any causal relationship to a particular type of transplant donor.

The previous analyses of patient survival by type of renal replacement modality does not consider other important patient outcomes, such as quality of life,

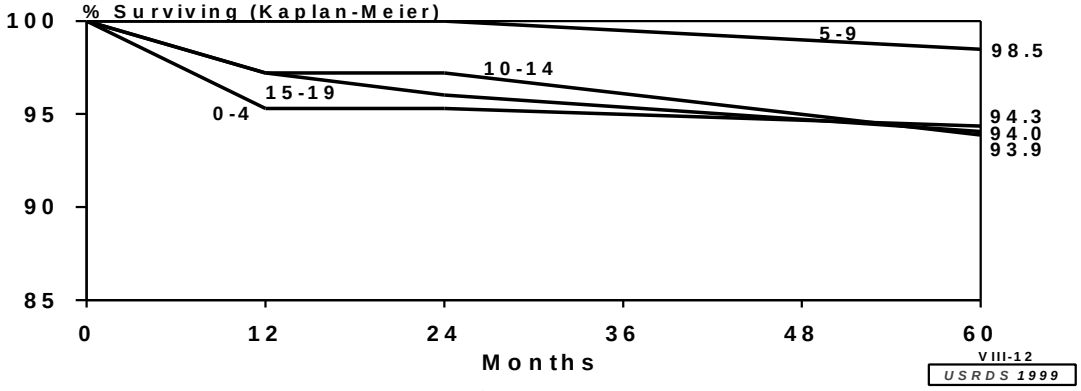

Figure VIII-12

Pediatric Kaplan-Meier 5-year patient survival estimates (percent) by age groups for all living donor transplant patients, 1991-92 transplant cohort. Estimates are unadjusted. Survival followup starting from date of transplant. Patients in Puerto Rico and U.S. Territories are included in estimates. Source: Reference Tables E.9, E.78, E.80, and E.82.

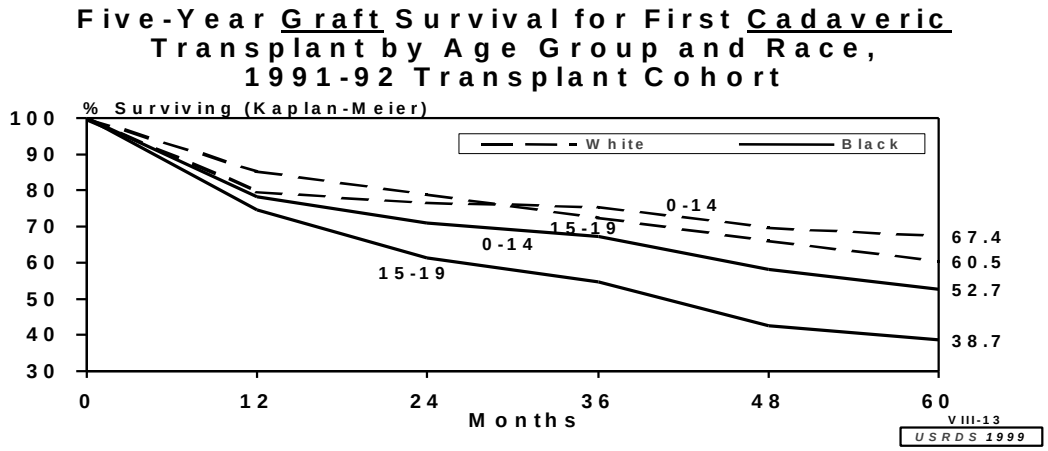

Figure VIII-13

Pediatric Kaplan-Meier 5-year graft survival estimates (percent) for first living transplants by age group and race, 1991-92 transplant cohort. Estimates are unadjusted. Patients in Puerto Rico and the U.S. Territories are included in estimates. Source: Special Analysis.

and growth that may also vary by modality. Any judgment concerning the relative success of a particular modality of care in addressing the needs of children with ESRD should consider differences in growth and quality of life in addition to survival.

Renal Graft Survival

Unadjusted Kaplan-Meier 5-year kidney graft survival estimates are shown in Figures VIII-13 and VIII-14 by age, race, and donor type, for all children transplanted between 1991-92. The first cadaveric graft 5-year survival shows a significant difference in survival by race. There is an almost 22 percent difference in 5-year cadaveric graft survival between the Black and White adolescent recipients, ages 15-19 years. The cadaveric graft loss in Black children is high with a range of graft survival of only 38 to 53 percent. Blacks in the oldest age group (age 15-19) have the lowest graft survival of 38.7 percent. The 5-

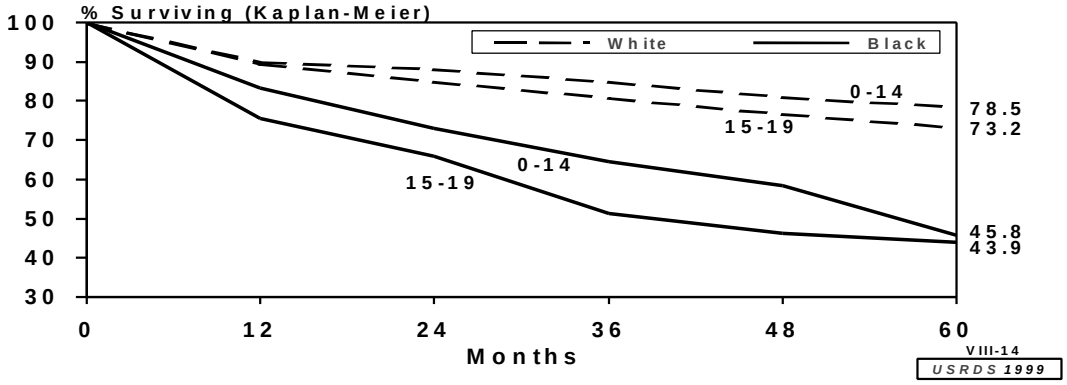

Figure VIII-14

Pediatric Kaplan-Meier 5-year graft survival estimates (percent) for first cadaveric transplants by age group and race, 1991-92 transplant cohort. Estimates are unadjusted. Patients in Puerto Rico and the U.S. Territories are included in estimates. Source: Special Analysis.

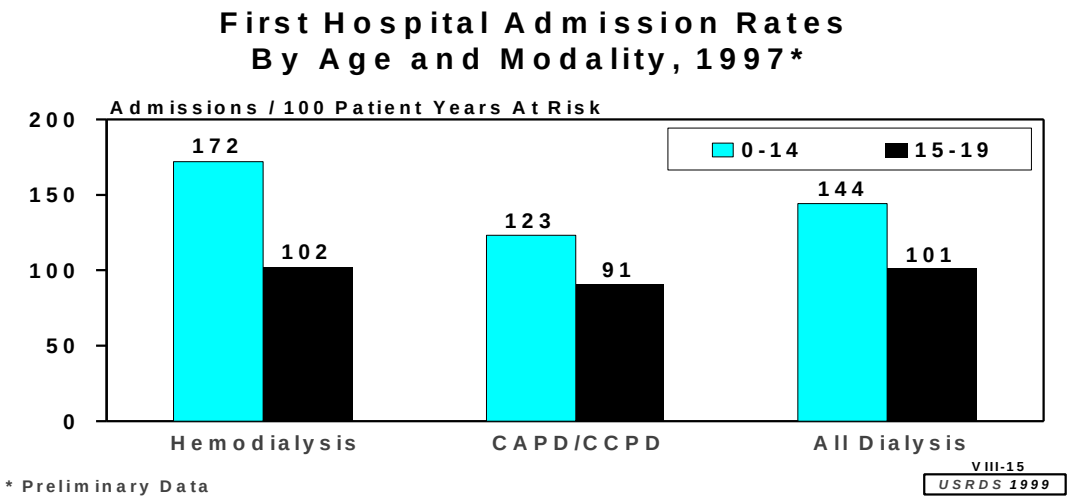

Figure VIII-15

Pediatric first hospital admission rates per 100 patient years at risk, by age and modality, 1995-97. Medicare patients only. Source: Reference Table H.1.

year first cadaveric graft survival does not vary as greatly in White children with survival of 60.5 percent in the oldest group (age 15-19) and 67.4 in the youngest group (age 0-14).

Figure VIII-14 depicts the living donor graft survival by age and race. The overall living donor 5-year graft survival is improved compared to the cadaveric recipients. However, the race differences in 5-year graft survival are still present even in the living donor grafts. There is an almost 30 percent difference in 5-year living donor graft survival between the Black and White adolescent recipients. White recipients had a 5-year living donor graft survival of 73-79 percent. The variation in survival with age in Blacks is much less in the living donor group compared to the cadaveric group. The 5-year graft survival for Blacks ages 0-14 is 45.8 percent and 43.9 percent in ages 15-19.

On the whole, Blacks had a poorer 5-year graft survival for either living or cadaveric donor transplants; in particular, Black teenagers have the worst graft survival. Graft survival estimates for recipients of other races are much less precise due to small sample sizes and therefore are not presented.

Hospitalizations

Figure VIII-15 depicts the first hospitalization admission rate per year per 100 patient years at risk in 1997. Among pediatric dialysis patients, there were more hospital admissions for the patients receiving hemodialysis than peritoneal dialysis. This may reflect a selection bias of patients initiated on hemodialysis, as peritoneal dialysis is still the preferred choice in the pediatric population. In the younger hemodialysis patients (ages 0-14), there was a significantly higher admission rate (172 admissions per 100 patient years) than for the older age group of 15-19 (102 admissions per 100 patients years). Refer to Chapter IX on hospitalization for more specific detail.

Mortality and Causes of Death

Deaths per 1,000 patient years at risk were analyzed by cause of death for all prevalent ESRD patients aged 0-19 years. Pediatric patients alive at the start of 1995, 1996, or 1997 were followed until death or until the end of the calendar year (see Reference Table D.4). The overall average annual death rate was 18.9 per 1,000 patient years for patients 0-19 years, and it is substantially lower than the rates for adult patients aged 20-44 years (57.1 per 1,000 patient years).

Figure VIII-16 provides the distribution of causes of death during 1995-97, for patients aged 0-19 years old after excluding those patients with missing as cause of death. (See Chapter VI for a more detailed explanation of causes of death). Infection was the most common cause of death in children (21 percent), followed by cardiac arrest (16 percent). The combination of cardiac arrest with other cardiac deaths accounted for 25 percent of patient deaths.

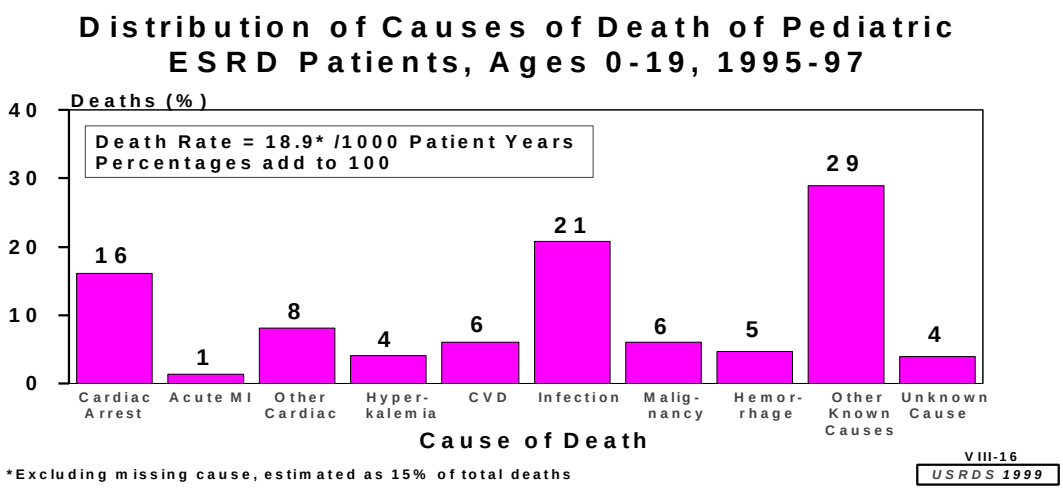

Figure VIII-16

Distribution of causes of death, pediatric ESRD patients ages 0-19 years, 1995-97. These percentages are calculated excluding those patients with missing data. Missing data are estimated and excluded from calculations. Patients in Puerto Rico and the U.S. Territories are included. Source: Reference Table D.4.

Note that the summation of cardiac arrest and other cardiac causes of death do not include hyperkalemia, which is listed separately as a cause of death. Also, cerebrovascular disease (CVD) contributes approximately 6 percent of deaths in the pediatric ESRD population. Malignancy accounts for 6 percent of deaths but this is not further differentiated into type of malignancy. Missing causes were excluded from these distributions, taking an estimated 15 percent from the denominator (See Chapter VI for a more detailed explanation of missing causes of death). Information pertaining to more precise cause specific death rates would be significantly improved with more complete reporting of cause of death by the treating nephrologists. The accuracy of reporting is important in the pediatric ESRD group as the assessment of cardiac and cerebrovascular deaths may have some implications in future management of patients (Parekh, 1998).

Comparisons of death rates for pediatric dialysis and transplant patients also yield interesting results (see Reference Table D.2 and D.4). The death rate for young pediatric dialysis patients (0-14 years), during 1997 was 56.8 per 1,000 patient years at risk. The oldest age 15-19 had a death rate of 32.4 per 1,000 patient years. The death rate for the hemodialysis patients, ages 0-14, was 50.4, and for ages 15-19 was 31.3 per 1,000 patient years at risk. The death rate for peritoneal dialysis patients was 66.5 deaths per 1,000 patient years in ages 0-14 and 30.7 deaths per 1,000 patient years in ages 15-19. There is a significant difference in the death rate of the younger patient on peritoneal dialysis compared to hemodialysis.

The average death rate was substantially lower in transplant patients who had an average death rate of 4.6 deaths per 1,000 patient years at risk. For adolescent patients (15-19 years) with a functioning transplant, the death rate was 7.3 per 1,000 patient years at risk. These data show significant differences in death rate by treatment modality. However, the data does not adjust for the possible effect of the sicker patients remaining on dialysis, not being offered a transplant, being waitlisted or having a failed transplant.

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